



**THE MEANING OF PREGNANCY LOSS:
IMPLICATIONS FOR HEALTH PROFESSIONALS**

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(ii)

I, the undersigned, hereby declare that the work contained in this thesis/~~dissertation~~ in my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

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UNDERSTANDING PREGNANCY LOSS: Implications for Health Professionals

Summary

In a qualitative study, eight participants were selected to represent the range of circumstances faced by women who have experienced pregnancy loss(es). Semi-structured individual interviews were conducted, transcribed and then analyzed, using grounded theory. These women seemed to fall into two main categories: those who wanted to be pregnant, and those who did not. Those who felt positive about their pregnancy, had seemingly attributed positive meanings to being pregnant and were overjoyed: then felt devastated when their pregnancy ended. However, those who were negative about being pregnant, had apparently attributed negative meanings to their pregnancy and were anxious: then felt ambivalent relief when their pregnancy ended. It therefore seems that feelings about their pregnancy loss(es) were determined by the meaning the pregnancy held for them in the first place and that this in turn, determined their needs at the time of their loss. Significantly, it was found, that regardless of whether they felt devastated or relieved by their loss, their immediate needs from doctors were surprisingly similar, whereas their longer term needs differed and in many instances, could only be catered for by an appropriate referral. Guidelines are offered for medical personnel in helping these women 'recover' psychologically in both the immediate and longer term with the core guidelines being a need for clinicians to listen to AND hear their patients and validate their experience.

SWANGERSKAP VERLIES:

Implikasies vir die gesondheidsberoepe

Opsomming

In hierdie kwalitatiewe ondersoek is agt kandidate, wat die wyer spektrum rondom swangerskap verlies(e) ervaar het, geselekteer. Semi-gestruktureerde individuele onderhoude is gevoer, neergeskryf en later met behulp van erkende teorieë geanaliseer. Dit blyk dat hierdie vrouens in twee hoof kategorieë ingedeel kan word: dié wat swanger wou wees en dié wat nie swanger wou wees nie. Dié wat positief oor hul swangerskap gevoel het, het 'n positiewe betekenis geheg aan die swangerskap, was gelukkig daarvoor en was na die miskraam uiters ongelukkig. Dié wat negatief oor hul swangerskap gevoel het, het negatiewe betekenis hieraan geheg, was angstig daarvoor en het na die miskraam ambivalente gevoelens van verligting getoon. Dit blyk dus dat die gevoelens oor hul verliese bepaal is deur die betekenis wat hul aan die swangerskap geheg het en dat dié betekenis ook hul behoeftes na die miskraam bepaal het. 'n Betekenisvolle bevinding was, dat ongeag of die vrouens verlig of onsteld na die miskrame was, hul huidige behoeftes aan 'n geneesheer soortgelyk was. Hul langtermyn behoeftes was egter verskillend en moet dikwels deur 'n toespaslike verwysing aangespreek word. Riglyne is opgestel vir die mediese personeel om dié vrouens te help met onmiddellike en langertermyn sielkundige 'herstel', met die kern riglyne dat die klinikus moet luister en hoor wat hul pasiënte sê en hul ervaring as geldig aanvaar.

FOREWORD

The central theme of this paper is that “context” is important. It therefore seems appropriate to give a brief history of the role that my context that has played in shaping it. Seven years ago I was “a wife” and an “expectant mother”. I’d been an expectant mother twice previously, but both pregnancies had been troubled and had ended in miscarriage: neither had any great impact on my life. However, that third pregnancy was different. I felt good, I looked good and everyone was excited and confident about the forthcoming birth of my identical twins. Without warning, one Monday, my first son was born blue and very dead and the second followed shortly crying like a little kitten. They were perfectly formed, but so tiny – when their heads rested on my fingertips, their little feet only just touched my watchstrap. I was shocked, shattered and shaken. My personal experience in hospital left me resentful at some of the insensitive treatment I received.

Another theme of this paper is that we construct our reality through our interactions with others. I therefore owe a thank- you to my gynecologist, Dr. Andri Nieuwoudt, who so powerfully shaped my experience with his warmth, sense of humor and sensitivity. Thank you for listening AND hearing, and then acting on my angry words. It was through him that I had a meeting with the matron of the hospital, which resulted in my training nurses and being a guest speaker at midwife and gynecological meetings. That was part of my healing. However, most of my healing came in the form of connecting with over four hundred women (and men) and hearing their experiences, both through attending a support group and corresponding with women all over the country and even some as far as Holland.

The voices of these women have all silently co-constructed and shaped this paper. To each and every one of them, I owe a deep debt of gratitude for the sharing of their very moving testimonies. I am also indebted to the eight courageous women whose words I

have borrowed to convey the message that we have very specific needs when we have a pregnancy loss.

It was the loss of my sons that started a new path in life for me. Not only did I search for and find a new spiritual path, but I also knew with certainty that I wanted to be better able to help people in need. I am now completing the final year of my internship as a Clinical Psychologist. This paper thus brings me a full circle: what was the initiating force for my study choice is also the closing chapter of the past six years and at the same time the beginning of a new chapter.

It was a sad chapter in my life history but I would not be without it. Looking back at my life's story, it has played a very central part in who I am and where I am. For that I am grateful for I am a better person as a result of this life-changing event.

Several people read, commented on and helped with earlier drafts. I would like to acknowledge the suggestions and comments of my father, Geoff Harris, my sister, Lara Valstar, Dr. Tessa Middleton, Hester Rabe, Monica du Toit, Adele Marais and Lenmarie Kruger. I also wish to thank my supervisor, Dr. Lou-Marie Kruger for her hard work, encouragement, thoroughness and insightful guidance throughout this study. I would also like to acknowledge the help of Marianna le Roux and Pia Konkol. A special thank you to my husband, Peter Corbet-Owen for his endless patience, sacrifice and support during not only this research project, but throughout my six year study period and our losses. Thank you too, to my parents and siblings who have always believed in me and hence allowed me to believe in myself.

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1. LITERATURE REVIEW

Various prevalence rates for pregnancy loss are reported: DeFrain, Millspaugh and Xie (1996) state that up to 33% of all women will experience a miscarriage, whereas Pines (1996) and Lee and Slade (1996) believe that about one in four first-time pregnancies will result in a spontaneous abortion. In addition, there were 8007 recorded stillbirths in South Africa in 1994 (Central Statistical Services). For the purposes of this paper, “pregnancy loss” will be used to refer to both miscarriages as well as stillbirths. A miscarriage is defined as the ending of a pregnancy before the time that the fetus could survive outside the mother without an elective abortion (DeFrain et al., 1996). A ‘stillbirth is the birth of a fetus that died before or during delivery’ (Glanze, Anderson, Urdang & Swallow, 1986, p.1073).

Pregnancy loss therefore affects many women and their families, regardless of culture, race, creed, ethnicity or maternal health. It follows then that, just as it is a universal phenomenon for children to be born every day, so is it universal for women to experience pregnancy loss daily (Rapp, 1994).

However, the individual’s significance attached to motherhood and therefore pregnancy, is *not* universal. As the latest research indicates, pregnancy seems to mean different things for different women, as its meaning is socially constructed and defined (Coslett, 1994; Ruddick, 1994). For some women therefore, pregnancy can be seen as a positive experience they desire, whilst for others it can be experienced as something negative that they do not want. Still others also feel ambivalent about being pregnant and can vacillate between joy and depression. Either way, pregnancy, is a profound experience for women. However many people may overlook this and act in ways which may be unhelpful at the time of pregnancy loss.

Epidemiological studies show that depressive episodes are twice as likely to occur in women than men (DSM-IV, 1994). Furthermore, the childbearing years appear to be a time of increased risk for onset of depression, and pregnancy loss may challenge the

already-at-risk, mental health of such women (Altshuler, Hendrick, & Cohen, 1998; Llewellyn, Stowe, & Nemeroff, 1997). Research suggests that pregnancy loss evokes widely divergent emotions such as relief, guilt, anxiety and depression (Lee & Slade, 1996). Furthermore, women who have miscarried often maintain a sense of loss, prolonged grief and unresolved mourning for many years (Pines, 1996).

While there are contradictory findings in trying to predict emotional adjustment after miscarriage (Lee & Slade, 1996), it would seem as if the psychiatric consequences of these feelings can include: depression (Beutel, Willner, Deckard, Van-Rad & Wiener, 1996; Lee & Slade, 1996), anxiety and somatic complaints (Frost & Condon, 1996; Lee & Slade, 1996) as well as posttraumatic stress disorder (Frost & Condon, 1996). Obsessive-compulsive disorder may also be exacerbated (Altshuler et al., 1998). Furthermore, a study by Wisner, Peindl and Hanusa (1996), found that the first lifetime onsets of both panic disorder and depression were common after a pregnancy loss.

In social constructionist theory, it is argued that reality does not exist, but is continually constructed by people in interaction with each other (Gonzalez, Biever & Gardner, 1994). In other words, the meaning of events in the world is not inevitable or natural, but is rather constructed by social actors, acting and interacting in the social world. Following social constructionist theory it can be argued then, that the meaning of pregnancy and of pregnancy loss can be different for different women, but that the meaning of the pregnancy and the loss will always be shaped by the social context within which the woman is functioning. Therefore, while on the one hand pregnancy and pregnancy loss can be seen as intensely private experiences, they nevertheless occur within a social context. Mead (cited in Andersen, 1983, p.221) writes: 'Whether childbirth is seen as a situation in which one risks death, or out of which one acquires a baby, or social status, or a right to Heaven, is not a matter of the actual statistics of maternal mortality, but the view that a society takes of childbearing'.

In understanding the emotional impact of pregnancy loss, it seems very important then to do research about how individual women negotiate the meaning of their loss(es) in the

various social contexts within which they are functioning. According to DeFrain et al. (1996), very few empirical studies on miscarriage have investigated psychosocial aspects of the phenomenon. Similarly, Lee and Slade (1996), believe that many of the factors studied have little to contribute to the understanding of the personal meaning of such a loss and that miscarriage has been neglected in research, especially certain aspects of appropriate psychological care (Keye, 1994).

There are many social contexts that are relevant in an individual woman's negotiation of the meaning of pregnancy loss. These contexts include the individual's own personal history, cultural context, socioeconomic context, the dominant gender discourses, religious context etcetera. This paper is concerned with the hospital or doctor's consulting room as one such context. For many women, remembering their baby's death means remembering what happened in hospital, so it follows that their treatment by medical personnel colors their memories (Yudkin, 1989) and shapes their lasting impressions. In a groundbreaking study, Beecher (cited in Epstein, 1995) showed how the meaning attributed by a patient to her experience, played a major role in the alleviation of anguish. For this reason, it is important to remember that health professionals can greatly influence, either negatively or positively, the meanings a patient attributes to her loss as well as her experience thereof (Epstein, 1995).

However, given it's high prevalence rate, it is somewhat distressing that, handling such a bereavement, seems to be one of the most neglected areas of a clinician's training (Johnson, 1996). According to McKegney (1995), medical students are purposefully trained to control their emotions, especially in times of crisis such a death, but are not trained to recognize, name, accept and honor their feelings. Nevertheless, they are expected to remain warm and compassionate. It thus seems self-evident that health professionals may play an important role in the psychological "recovery" or "lack of recovery," of these women in several ways.

However, it needs to be recognized that both "patient" and "doctor roles" are defined by existing discourses of power. It seems that the power and authority inherent in the title of

doctor have a powerful effect on the way women patients experience pregnancy loss(es). In addition, if the doctor is male and the patient is female, the doctor-patient relationship is likely to reflect not only the dominant gender roles of that society but also the roles of professionals and their patients. Both the doctor and the patient are therefore likely to have expectations of the other that are conditioned by the status each occupies (Helman, 1990). In South Africa, the large majority of women will see male doctors as by 1994, only 13,7% of general practitioners and 5,5% of gynecologists in South Africa were women (Central Statistical Services).

The specific aims of this research are to:

Gain insight into the emotional impact of pregnancy loss on women.

To understand women's emotional needs after such a pregnancy loss.

To generate suggestions as to how women can best be supported by medical personnel, so as reduce their immediate psychological distress as well as their long-term chances of developing a psychiatric disorder.

2. RESEARCH METHODOLOGY

This paper reports some of the results of an exploratory study in which the emotional impact of pregnancy loss on women was investigated. It was hoped that such an explorative study would generate ideas about what women's emotional needs after pregnancy loss would be.

Purposive sampling was used to recruit eight Afrikaans-speaking and English-speaking women living in the Western Cape. As women who have had a pregnancy loss are not a homogeneous group, participants were recruited to represent a range of different circumstances that is different cultural and racial groups, different socioeconomic groups, different religious backgrounds etcetera (see Table 1). It was also decided to attempt to include women with different kinds of experiences of loss that is number of losses, number of children, stage of pregnancy during which loss occurred etcetera (see Table 2). It is problematic to conduct open-ended interviews in the second language of the

participant or the researcher (see Burke, 1999; Potgieter, 1997). Therefore as the researcher (who was also the interviewer) is fluent only in Afrikaans and English, women who did not speak either of these languages as a first language were excluded. This means that no African women participated in the study. Recruitment strategies included referrals by nursing staff and word of mouth.

Table 1

Demographic details of women participants

Name	Reported relationship with partner		Current Relationship	Financial Context		Religious Context		Home Language			PSYCHIATRIC HISTORY
	Poor	Good		Working Class	Middle Class	Not NB	Not NB	Eng.	Afr.	White	Colored
Jackie	X		Re-married	X		X		X		X	x
Judy	X		Separated	X			X		X		X Alcohol dependency
Libby		X	Separated		X		X	X		X	X
Nicky		X	Happily Married	X		X			X	X	"Nervous breakdown"
Sandy	X		Re-married		X	X		X		X	X
Sonneblom	X		Widowed	X		X			X		X Complicated bereavement
Susann	X		Unhappily Married	X		X			X		X Depression
Ursula		X	Married	X		X			X		X Alcohol dependency

Table 2

Details of Pregnancy Loss(es)

Code name	Age(es) at time of loss(es)	Number of other children	Desire for pregnancy		Plans for pregnancy		Number of loss(es)	Sex of child lost	Stage of pregnancy at loss(es)
			Yes	No	Yes	No			
Jackie	28	2	X		X		1	Girl	Full-term
Judy	29	2	X				X 1	Girl	22 weeks
Libby *	23 - 30	0	X		X		4	Unknown	9 weeks
			X		X			Boy	21 weeks
			X		X			Boy/Girl	20 weeks
			X		X			Girl/Girl	26 weeks
Nicky	19 - 22	0	X		X		3	Unknown	16 weeks
				X	X			Unknown	28 weeks
			X		X			Unknown	28 weeks
Sandy	28	2	X				X 1	Unknown	12 weeks
Sonneblom	28	4	X				X 1	Unknown	5 weeks
Susann **	23 - 25	0		X			X 2	Boy	24 weeks
		2		X	X			Boy	16 weeks
Ursula ***	18 - 33	0	X				X 3	Boy	24 weeks
		2	X					Girl	20 weeks
			X					Boy	32 weeks
Libby*	Fertility treatment, surrogate mother attempt, in-vitro and finally adoption								
Susann**	Struggled to fall pregnant								
Urusla***	Unmarried with first pregnancy								

Each participant completed a biographical questionnaire (see Appendix 1 p.41), chose a code name as used on the above-mentioned tables, and voluntarily signed to give informed consent (see Appendix 2 p.44). Open-ended, semi-structured interviews were conducted in the same six-month period by the researcher who is a masters student in clinical psychology (see Appendix 3 p.46). This type of interviewing is appropriate as it allows participants to freely formulate their own rich stories (Anderson & Jack, 1991;

Babbie, 1994; Emerson, 1988; Mishler, 1991), in their own language which reflects their own unique understandings constructed within their particular contexts.

Participants were told that the interviews might bring back painful or difficult memories and that appropriate referrals would be provided if needed. One of the participants was actually referred for psychological counseling after the interview. All interviews were taped and transcribed verbatim by the researcher using Silverman's (1993) and Riessman's (1993) guidelines (see Appendix 4 p.49). The data was analyzed using grounded theory techniques as described by Charmaz (1995). In grounded theory research, actual data collecting and transcription are not regarded as processes that are completely separate from data analysis (Charmaz, 1995), but rather as the first major analytic phase of the research which consists of the coding of the data. In the current study, line-by-line coding was used to name each line of data and to generate a wide range of "initial codes". The purpose of line-by-line coding is to force the researcher to keep close to her data and 'to see the familiar in a new light' (Charmaz, 1995 p.38). A list of codes that continually appeared during initial coding was compiled (see Appendix 5 p.50). This list of 25 codes was then used in a second round of "focused coding" during which all the interviews were coded again in a more purposeful coding process. During focused coding the researcher tries out possible conceptual categories that she thinks may have overriding significance in her data. In the current study, this process involved the compilation of a new "memo" for each participant in which data was systematically organized into each coding category (for example, see Appendix 6 p.51). These coding memos served as the basis for the discussion of the results that follow. When working with data from Afrikaans-speaking participants, translations were done from Afrikaans into English and then translated back into Afrikaans by a second translator (Benjafield, 1994).

3. RESULTS AND DISCUSSION

While the study yielded many interesting results regarding the emotional impact of pregnancy loss on women, the focus of the current paper was on how medical health

professionals can shape the emotional experiences of women in positive and negative ways. Relevant findings are discussed by:

- 1) Reporting how participants of this study describe the actual impact that medical personnel had on their experiences of pregnancy and loss;
- 2) Exploring how participants understood and experienced pregnancy and pregnancy loss; and
- 3) Analyzing participant's immediate and longer-term emotional needs and the possible roles medical personnel can play in fulfilling those needs.

3.1 Medical context

The fact that patients have particular expectations of doctors and that these expectations are often not met, has been well documented in the literature (Hauser, 1981; DeFrain et al., 1996). In the current study, a number of participants clearly stated their disappointment with how they were treated by doctors. This disappointment is not limited to the medical treatment they had received, but also includes a disappointment or anger about the lack of respect with which they were treated in general. Judy says:

"So I started accusing and blaming the doctors. I started to think the doctors could have done something...then my child would have lived. The doctors were useless..."

Ursula and Jackie respectively say:

"...angry with the doctor... in the first place he could have admitted me"

"How DARE he decide that I can't see that baby."

In more extreme cases, participants blamed the doctor for playing a malicious role in their loss. For instance Susann says: "... it felt to me as if he was aware of what he was doing... because afterwards I found out that his wife lost every baby she was expecting. I got the impression that morning that he was not giving me the privilege of keeping my baby because his wife couldn't keep hers." While some of the participants are able to articulate their anger and disappointment, most participants comment on how powerless they felt in the doctor-patient relationship. It seems that they are saying that their position as patient was inevitably one of disempowerment, while that of the doctor was one of ultimate power. Jackie, clearly conscious of how the doctor's power is also linked to dominant gender discourses says:

“... it was a chauvinistic world I lived in and you didn’t argue with a man, ESPECIALLY if he was a doctor... the doctor was, always knew best and he MUST know best. He didn’t know best.....”

“I remember that the doctor was close to God and you never questioned a doctor.”

Other participants voice how they feel stripped of power by their seeming inability to ask questions, as well as the expectation that the suggestions/instructions of medical professions are to be followed without question (Lupton, 1994).

Judy and Jackie respectively say:

“What the doctor gives us is never questioned...”

“I believed him implicitly and it actually didn’t work out that way.... he didn’t make allowances for the event not to happen....I believed in him like I believed in the Bible” (Jackie)

Some of the other comments about a doctor’s power include: “...have TOTAL faith in them”, and “I really believed...” (Libby); and “when I knew I was pregnant, the doctor said ‘you are not’ so I accepted his word” (Judy).

These participants tell us that their belief in these powerful doctors was total, but that they have since realized it was also misplaced. Women patients such as those with a pregnancy loss are normally conscious and capable of expressing wishes and feelings but have often been socialized into suppressing their needs and being dependent on, and co-operative towards clinicians (Hauser, 1981). Therefore a doctor’s power is partly enforced by a woman’s unconscious self-monitoring in line with the dominant discourses of our society (Lupton, 1994).

Maguire (1992, p.18) writes: ‘We all recognize power when we see it – or do we? We know the exhilarating feeling of exercising power ourselves. We also recognize the feeling of being on the receiving end of power’. However there seem to be disquieting gaps between medical power and maternal (em)power(ment). Women in this study, share with us the ways in which they believe their experience is shaped by being on the receiving end of treatment by more powerful doctors. The narratives of women about the effect that even doctors’ suggestions have on women are powerful.

Jackie says:

“...this little white coffin that we carried, I thought, I can open it and look, I mean it’s right here in my hands, I can look, but I felt as though I would have been naughty. Isn’t that silly. It’s MY child and MY right to look at what came from ME and I was intimidated into not even then looking at the baby...”

Ursula says:

“ he told me what to do and I did what he said...”

Participants clearly tell us how powerfully medical professionals can shape their experiences, be it by insensitive suggestions or labeling which influences not only the way women felt about themselves, but also the actions they did or did not take. Some of the difficulties experienced may revolve around medical helpers being unaware of how his/her particular responses might trigger conflicting feelings in women which can have long-lasting effects (Hauser, 1981). The literature powerfully suggests then, that medical professionals are very influential in shaping the meaning of medical procedures or physical traumas of their patients. The participants of the current study reiterate the power of medical professions. If this is true, it is imperative to determine how these professionals can play a positive role in the emotional processing of pregnancy loss. It is this question that the researcher attempts to answer in the following sections.

3.2. Wanted pregnancies and pregnancy loss: meaning-making and emotional impact

While many women feel some ambivalence about being pregnant, most women can also say whether they felt that a pregnancy was generally wanted or not. The meaning-making processes and emotional sequelae of these two groups of women are discussed separately because of the different meanings each group attributed to their pregnancy and their loss. It would also have been possible to divide the women into other groups (i.e., religious vs. non-religious, white vs. colored, low income vs. middle class etcetera) and this will certainly be done for future papers. However, in terms of how they understood and felt about pregnancy, the clearest dividing line in this particular group of participants, had to do with whether the pregnancy was reported to be wanted or not.

Rosaldo states (cited in Wetherall & Maybin, 1996, p.235): 'feelings are not substances to be discovered in our blood but social practices organized by stories that we both enact and tell. (Feelings) are structured by our forms of understanding.... Feelings are social practices'. It thus becomes obvious that the way women feel is influenced by cultural guidelines as to how they should/ may react in circumstances, such as a pregnancy loss.

Some of the women with wanted pregnancies report feelings of cautious joy and ambivalence. Jackie and Susann respectively say:

"...big...full of energy... feeling absolutely great" and "...huge and lumbering."

"...was a bit shocked... (it) wasn't something I had planned...couldn't believe that I was pregnant... so full of joy".

While both participants were glad to be pregnant, they seem to have mixed emotions but clearly describe their pregnancies as wanted. However, when pregnancy was wanted, the voices of most women were filled with excitement, confidence and pride. For instance, Nicky says: "I was absolutely through the roof...very excited" and "really, really happy"

Other phrases used to describe the experience were: "over the moon", "just loved the idea", "on top of the world" and "mind-blowing" (Libby); "feeling absolutely great" and "very excited" (Jackie).

Often this happiness and excitement seemed to be related to a sense that being pregnant was a normal and status-enhancing part of being a successful person and a dutiful wife. Thus some participants report that being pregnant is to fulfill what is expected of a "normal/proper woman" or the norms of appropriate feminine behavior in our contemporary society. After all, it seems as if 'Women's mothering is one of the few universal and enduring elements of the sexual division of labour' (Rose, 1994, p.43).

Nicky says:

"It was just something that's normal, it's supposed to be. It's the way you're married now and you have to... you're going to have children "

Other participants used phrases like, "whole person " and "mission in life" (Libby) and "just something that HAD to happen" (Ursula).

These women are stating that pregnancy is something that should be seen as desirable, to be expected and in fact an inevitable part of heterosexual married life. Ruddick (1994), has observed that much of the identity and empowerment of women is defined by their role as mother. For many, it is viewed as being “the ultimate aim” for all women as it is considered to be the “natural”, “inevitable” and the “right thing to do” (Wearing, 1984).

It could be said that the meaning humans attribute to events, are partly formed by the pressure to adopt sex-appropriate behavior and as such, is evidence that the socialization process controls women in several ways. Socialization defines women's roles and how they are expected to act and react in certain situations (Andersen, 1983) for example “as women”, “as wives” and “as mothers”. It also provides our definition of others and our relationship to them (Andersen, 1983) for example, “wife of”, “mother of”, “or patient of”.

Women appear to be defined as “nurturers” and “carers”. Their identity and status are thus derived from their relationship to the explicitly gendered categories of mothers and wives (McDowell & Pringle, 1992). To fall pregnant is then in some cases more than simply inevitable, it is an achievement, it is to finally achieve the status of nurturer.

Nicky says:

“I was more confident of myself... It gave me a boost, you know, I've achieved something.”

“I was absolutely the best person in the world... made me feel that I've now done something on my own.”

“It was like a medal... it was better than being a teacher or being a... I was good, I was DAMN good!”

Libby says:

“People do kind of treat you a little bit differently, maybe make you feel a little bit special.”

“...every loss was making me more and more determined to have a baby... I think the actual baby had become almost a secondary issue – the pregnancy and getting to term was becoming... the main issue”.

“I got far enough for them to be born alive and now they just HAD to survive, it didn't matter in what condition”.

For Nicky, pregnancy improved her self-esteem and status. However, Libby seems to be saying that even having a handicapped or retarded child would give her more status than

having no children. Feminist authors have showed how motherhood is often experienced as an achievement to be proud of, and is thought to give women a unique sense of social value that is difficult for them to achieve in other areas of public life (Phoenix, 1994; Simon, 1984).

Conversely, when falling pregnant proved difficult for Susann believed she was defective. She says: "Why can't I fall pregnant? ...thought there must be something wrong with me..."

When struggling to fall pregnant, Nicky's sense of being unsuccessful seemed to be so threatening, that having a baby becomes almost an obsession. She says: "I was just adamant I'm going to have a baby. My main brain.... Baby, baby, baby, baby. I'm going to prove to everybody that I am able to do this and I can do it and I will do it. I was paranoid about it."

Both Susann and Nicky feel that they are somehow unsuccessful when they are not able to achieve what should be normal and natural. As Coslett (1994), points out, there are essentialist tendencies in discourses about women that assume all women should be mothers: those who do not fit the prescription are marginalized.

Some participants also suggested that by being pregnant, they are fulfilling their expected duty as "good and dutiful" wives.

Nicky says:

"It was natural to have a baby with him."

"What a joy would it have been if I have a little baby born on his birthday ... It would be just the ultimate!"

Susann says:

"...so that I can prove to my husband I can have babies. ...he also really wanted to have a baby."

"...to show him I love him"

Other participants use the following phrases to describe the importance of providing their husband with a child: "...to have D's baby ...wasn't important to him, it was important to ME" (Libby); and "... "then my whole life would have been different... marriage would have recovered... family bonds would have been stronger..." (Judy).

It therefore seems that in being a dutiful wife to your husband, pregnancy can become a powerful instrument for fulfilling his needs, showing your love for him, sharing the relationship with him and in some cases even saving or strengthening that relationship. Women who felt that they wanted their pregnancies tended to talk about the meaning of their pregnancies in essentialist terms. They saw it as inevitable and natural, as a status-enhancing achievement and the fulfillment of a duty to society and their husbands. It can be expected that when pregnancy is understood in these ways, pregnancy loss will also be experienced in very particular ways.

Women who do not live up to, or who fall short of the ideals the dominant female images of our society, are encouraged to feel inadequate (Maguire, 1992). When the pregnancy was wanted, it seems that a pregnancy loss encouraged women to think of themselves as failures with reduced status because they were unable to fulfil the expected role of dutiful wife. For instance Nicky voiced that her inadequacy was so great that she felt totally worthless. She says: "... I felt like.... a waste".

For many participants, the theme of their loss seems to center on their body's failure, almost as if it is easier to accept that there is possibly a medical reason for their loss.

Nicky says:

"I'm so thin and ... I'm so anemic. Maybe that's why I've lost a baby.... Is my body wrong?"

Libby says:

"It's just something that my body failed..." but she denies feeling like a personal failure only when she is able to justify other areas where she has succeeded. She says: "I don't think that I've ever really considered myself as a failure... we've always had a good sex life" and "I've never really felt that I've failed as a woman because I look at myself now... and I KNOW I'm a good mother."

Speraw (1994) and Keye (1994) point out that many women may believe their partners have fulfilled their obligation by making them pregnant, and then regard themselves as reproductive failures and feel guilty for not being able to fulfill their side of the bargain. For Libby this meant her husband should be freed to find another more 'successful' wife. She says: "... he must go find a woman that can give him a child because the problem is not his, it's

mine” and “He was medically or scientifically capable of having a child of his own and I wasn’t able to give it to him.... I didn’t want to live the rest of my life knowing that I was the reason that he didn’t have a biological child. I didn’t think I could face it”.

For other participants, not being able to fulfill their husband’s needs attracted a host of negative consequences. They say: “...he will commit suicide”, “...he shouted at me”...“he will look elsewhere for a women who can raise children for him” and “ I shouldn’t bother to phone him to ask him to come and fetch me, I must rather go straight to my mothers (when I am discharged)” (Susann); “...blamed me...and now he has a baby girl with another women” (Judy).

It seems therefore as if the expectations of women for failing to procreate was that they could not expect their husbands to still want them and were almost deserving of any consequences, even having a husband who has a child with another woman.

We see then that this group of women understand their pregnancy loss not only as a personal loss, but as a failure to function properly as a woman and to fulfil their duty. It is not surprising that their pregnancy loss left them feeling shattered, disconnected, guilty and alone (Beutel et al., 1996).

Nicky says:

“Sad, sad ...just sad.. I felt so sad for this little thing that I flushed down the toilet. It still hurts me now...”
 “...I was very, very heartbroken...I can’t say to you how I felt then, I was heartbroken.”

Other participants describe the sadness as follows: “devastated” and “heartbreaking” (Libby); “the whole world was crying with me”, “my world was falling apart”, “absolutely shattered” and “very depressed” (Jackie); “felt hurt” and “painful” (Ursula); “sad but...shamed” and “felt bad” (Susann).

Other feelings mentioned by Beutel et al. (1996) were also described: “I felt very alienated... very disconnected” (Libby); “...was so isolated” (Jackie) and “total bottomless emptiness, nothing” (Nicky).

However, some women deny the implications of their loss and have feelings of disbelief and emotional numbness as they block out other intense emotions (Lee & Slade, 1996).

Jackie says:

“I was in a state of unreality really. It doesn’t feel like 27 years ago...I was in complete denial.”

“I didn’t believe, I really believed the baby... half of me believed the baby was alive.. struggle between the baby being alive and the baby being dead.”

Other participants say, “...was shocked” (Susann); and “...like it wasn’t me..but it was me...” (Libby).

One of the intense emotions women find the most difficult to block out is guilt especially when they are left to feel the pregnancy loss is their fault (DeFrein et al., 1996). Jackie and Nicky respectively ask: “...did I do anything to cause the baby to die...?” and “Where have I failed ?”

These women tell us they felt heartbroken and sad, alienated and disconnected, shocked and guilty, and in denial about believing their baby was dead. Seeing their descriptions can leave the reader in no doubt that pregnancy and any ensuing loss was a powerful and profound experience for them and that their feelings include many of the usual symptoms of grief (DeFrain et al., 1996; Keye, 1994).

3.1 Unwanted pregnancies and pregnancy loss: meaning-making and emotional impact

Another group of participants seemed not too eager to become mothers. In stark contrast to the previous stories, participants whose pregnancy was not wanted report nervousness, desperation, uncertainty and being joyless at the thought of being pregnant. Lee and Slade (1996) echo what these participants say when they report that, when pregnancies are not planned, women feel anxious due to ambivalence and guilt.

Sandy says:

“I desperately didn’t want this baby...“I was in a terribly nervous state, I was besides myself.”

Nicky says:

“....made me feel horrible.... terrible... uncertain...” and “There was no joy on having been pregnant (sic). There was no joy. There was no happiness...”

Those participants who did not wish to be pregnant, voice feelings of emotional turmoil

as they view their pregnancy as being unnatural, a symptom of being misused, losing their freedom and being disillusioned with married life.

Nicky says:

"It was something unnatural um.... I didn't even want to talk to the baby... It made me feel very funny."

Sandy says:

"Um.. the pregnancy itself wasn't a pregnancy that I wanted, I didn't want it at all..."

"I was always sitting at home, I was always looking after the kids... there was a better life out there."

"It would have been terrible. I don't know how I would have handled taking that baby home..."

Sonneblom says:

"I was used. He didn't give me a chance to heal as a woman again and then he wanted me again."

"The children are still small...I can't even cope with them"... "little choice... very little choice... is this married life?"

It seems that in a less explicit way, these quotes also suggest that there is a particular understanding about what women's inevitable roles are. Yet this group feels resentful about how such roles are almost forced upon this. This group seemed to feel that pregnancy is an unwelcome burden. When pregnancy was perceived negatively, its loss was viewed as a reclaiming of their freedom. Sonneblom and Sandy respectively say:

"I am glad it happened otherwise I would have been sitting with 5 children..." and "a difficult time because as a wife who was loyal to my husband... I felt I had had a loss".

"It was a relief. All I wanted was relief and my relief was getting rid of my baby."

Interesting enough, just as with those women whose pregnancies were desired, some also experienced it as a loss of status and confirmation of not fulfilling their duties as women and wives. However, even when they can to a limited extent recognize a sense of failure or loss, they do not feel sad about it. It seems that the narratives about loss when the pregnancy was not wanted are filled with relief, even if this relief was tinged with shame and regret. Sonneblom says: "I'm sorry to say this but I am glad it happened..."

Sandy's ambivalent and mixed up feelings are clearly stated when she says:

"Um...relief, but not, I wouldn't say it was a happy relief... relief in my subconscious..."

"It was a lonely time... inside I was empty...I wasn't proud of myself."

Sonneblom seems to feel shame at being glad her pregnancy is over whereas Sandy's relief is mixed with shame and feelings of being alienated and alone. In general this group of women was much more reluctant to talk explicitly about the meaning of pregnancy loss for them. This may indicate that it was simply not as an important experience to them. Very little has been written about the meaning of spontaneous pregnancy loss when the pregnancy was not wanted. This again highlights the fact that even in psychological discourses regarding pregnancy loss, there are essentialist tendencies: those women who are not distressed by pregnancy loss are not represented in the literature. Whilst there is much literature on women, pregnancy, and feelings surrounding elective abortion, there appears to be a veil of secrecy on women's feelings when spontaneous pregnancy loss is wanted. There seems to be a taboo on wanting not to be pregnant and then being simply glad or relieved when a pregnancy loss occurs. It is evident that current discourses give women contradictory messages. On the one hand they seem to dictate that pregnancy loss is trivial and yet on the other they seem to dictate that if a woman feels positive about such a loss she *should* feel guilt/ shame that she actually felt glad or relieved about her loss.

3.4 Womens' immediate needs from medical personnel

In the previous sections, it was illustrated how women can attribute very different meanings to pregnancy loss and can therefore have very different feelings about the experience. It was clear that some women felt devastated by pregnancy loss, while others felt relief. What is remarkable then is, despite the range of feelings about pregnancy loss, all the women in the study articulated having similar needs immediately after their loss. Regardless of how they understood the loss or how they felt about it, they all felt an intense need to have their thoughts and feelings validated through being listened to AND heard. However for women to feel they can honestly share their experiences, they need to feel safe and in control rather than feelings that they are being controlled (Herman, 1992).

Patients often attempt to introduce topics reflecting their concerns and feelings. Many doctors, however, typically attempt to get back to their clinical agenda, leaving these patients to feel that their voices are neither heard nor understood (Birenbaum, 1995). According to Rosenblatt (1995), 'The essential tool for the physician is ...the ability to place the patient in a context' (p15) and this can only be done by gently probing for, then **listening AND hearing** patients' own personal definitions and understandings of their experience (DeFrain et al., 1996). This need to be heard and taken seriously was very powerfully reiterated by the participants.

Sandy says:

"A doctor should really sit and talk to his patient and really find out ... I wouldn't say what their lives are all about but if that baby is really wanted. The doctor should TRY to establish that, he should."

Judy says:

"The doctors have the medical knowledge, but it's the person who knows when something is wrong with her body. I'd like the doctors to have more belief in what you say because YOU know what you feel."

Women indicate, they have a need to feel that they are understood and that their opinions are respected. Sandy seems to be saying that the doctor did not understand her context, but merely treated her from his own assumptions. Judy, however seems to feel frustrated that her knowledge was not taken seriously.

Libby, however, tells us of her positive experience when she felt listened to and heard.

She says: "...gyne (sic) arrived he was ABSOLUTELY wonderful, totally sympathetic, had all the time in the world to sit and explain and discuss and let us ask questions."

It seems that doctors may not listen for a number of reasons. Firstly, the medical context is physician-centered and their training seems to emphasize brief conversation in which more value is placed on their intellectual skills than their communicative skills (Helman, 1990). Additionally, medical workers may also have their own assumptions that are formed not only by their medical knowledge, but also by their own personal beliefs and cultural expectations. For example, Speraw (1994) cites research where health care workers assumed that women should be relieved at their loss because the fetus could have

been defective. On the other hand, some doctors may presume that *all* women will feel psychologically devastated by a pregnancy loss. This is not Sandy's truth, she says, "He thought I was having a great loss ... he didn't know my true feelings... he didn't know that it was a relief in my life." Helman (1990) makes the point that to be effective, medical professionals need to understand how a patient expects an event to impact on her life and what their emotional reactions to the event are.

In addition, it is not uncommon to have the psychological investment in an unborn baby underestimated in a society that does not validate (Lee & Slade, 1996) but rather dismisses it as being a 'mere miscarriage' (DeFrain et al., 1996, p.335). In the absence of societal support, women may hope that their experience will at least be **validated and acknowledged** by their doctors, as it brings relief to have their feelings legitimized as valid (Leppert, 1984).

Libby and Judy respectively say:

"... really felt that it needed to be ACKNOWLEDGED. I felt that by ignoring it, people were saying that they were never really born and they never really existed and that drove.. it really used to frustrate me."

"It was as if nothing had happened. People soon forgot about it..."

Medical training does not appear to include making the shift from healer to counselor/consoler, therefore a woman's expectations may exceed what services the doctor is able to, or willing to supply (Knapp & Peppers, 1979). However, when the doctor *is* able to acknowledge and validate the reality of her baby, it contributes to relieving Nicky's distress. She says: "I said to him but I want to know what this moving is, what was jumping and kicking and tiny little movements .. said to me, 'sweetheart, it was the baby' and you know that meant SO much to me... it WAS MY baby. It was my baby."

When pregnancy loss is not validated, women are more susceptible to suffering from unresolved grief (Lietar cited in DeFrain et al., 1996).

Susann and Sandy respectively say:

"...don't keep your grief in... later you could land up with depression..."

"I started drinking after my miscarriage... it would relax my mind"

These women are saying that when they felt that mourning was not appropriate, they halted their grieving process and developed other symptoms or coping mechanisms. Beutel et al. (1996), agree that when women are unable to voice their grief, other signs become the idioms for their distress which may lead to long term psychological consequences.

Related to the need for validation is the importance of collaboration and negotiation between medical personnel and patients (Clark & Mishler, 1992; Reader, 1989). When patients are conscious and capable of making decisions, they have a **need for health care workers not to intervene with their own assumptions** but rather to decide in collaboration with them (Scott, 1994).

Jackie says:

"The nurse who asked me what I had done was not good ...- she was making a MASSIVE assumption."

"How DARE the doctor decide for me that I can't hold my baby?"

Libby says:

"SHE at that point had made her decision . I don't feel that she had any right to make that decision for us."

Participants are saying that to merely assume and to make decisions for patients is unhelpful and often results in oppositional feelings. So while it is foreign to their training, it seems it would be helpful if medical professionals understood women from *their* viewpoint rather than simply seeing how they fit into the practitioners theories (Gonzalez et al., 1994).

Knowledge is power and is used to exercise social control (Maguire, 1992). So, just as (scientific) knowledge creates power for doctors (Helman, 1990), it appears that by having access to this knowledge, women would also feel more powerful, more in control and safer. As far back as 1964, Cartwright found that many patients were dissatisfied with **information and explanations** from physicians and it seems as if this view still prevails. Susann says: " He did not explain to me...no-one actually tell me why I have miscarriages."

De Frain et al. (1996) found that when doctors could not give patients a reason for their loss, 67% blamed themselves in the absence of needed reassurance, and guilt appears to be the most difficult emotion for women to resolve without help (Leppert, 1984). Jackie, when not given an explanation resorts to self-questioning and self-blame and feels that any explanation, even if it was incorrect, would have saved her guilt. She says:

“... explanation of why that baby died would REALLY have helped, even if he made something up...”
 “...did I do anything to cause the baby to die...?”

When her first loss occurred, Nicky had no explanation but with the second she does. Not being given an explanation leads to her having repetitious thoughts of how she has failed. She says: “...there is no explanation ...” When asked: “if someone had explained to you how your baby had died?” She replies: “I wouldn’t have been having all of those questions inside of me...Where have I failed?” However, when given a sensitive, even if less accurate explanation, she appreciates his sensitivity and is not plagued with unanswered questions. She says: “..he said to me, he want (sic) to explain to me... it wasn’t a baby.it was a cyst.. He explained it in that way.. I know it wasn’t something like that, you know, it must be something more horrible...”

Libby’s gynecologist seemed to take extra care to give explanations and discuss the implications of various options so that she could feel in control. This she describes as having been a positive experience for her. She says: “He totally, he analyzed the whole physical thing... what had went wrong and you know why it had happened and all the questions that we asked, he explained everything ...”

Professional information given to patients in terms that they can understand has been linked to improved outcomes (Bader & Braude, 1998), especially if clinicians emphasize that it is nothing that women did, or did not do, that would have prevented the loss (Keye, 1994). Participants seem to support that receiving information, even if it was inaccurate, was helpful whereas having no explanation was a cause of distress for them.

Cecil (cited in Lee & Slade, 1996) found that patients complained of insensitive and unsympathetic care from medical staff. Participants agree.

Jackie and Libby respectively say:

“I can’t really put any blame other than the insensitivity from that nurse and maybe the doctor ...” and

“Nurses need to be VERY sensitive.”

“My initial experience...was hideous.... TOTALLY unsympathetic, starting screaming and shouting at me to calm down and control myself otherwise I would CAUSE the miscarriage.... Nightmare.”

It seems that these women experienced insensitivity at the hands of both doctors and nurses. Lee and Slade (1996), point out that **sensitive care** after pregnancy loss was helped mainly by personal contact in clinicians’ own lives with this experience, rather than through their training. This could imply that until a person has experienced a pregnancy loss they do not understand the impact it may have.

In hospitals, there appears to be a split between curing and caring. Stereotypically, nurses supposedly are the nurturers, whereas doctors are the expert healers. Such a division may not work in the best interests of patients (Andersen, 1983). A study by Plaja and Cohen as far back as 1968, shows that few doctors were regarded as empathetic and women in our study echo these findings. Susann says:” They didn’t care... their attention was with the other mothers who had babies...” and “just always hurried with me”.

Other participants use terms like: “Cold... nobody bothered” (Nicky); “he was so offhand” and ‘it would have helped to have a caring doctor” (Jackie).

However, some participants had aspects of their care that was helpful.

Jackie and Nicky respectively say:

“... appreciated the way the nurses grieved with me and couple of them, really were very heartbroken”

“...all the nurses... they CARED for me. They cared for me...they KNEW what I was going through.”

“EXCELLENT gynecologist! He’s a HUMAN BEING.. he’s like a father....”

It seems that women wish to perceive their caregivers as feeling human beings, that can display compassion. This is also supported by DeFrain et al. (1996). In addition, women tell us that previous pregnancy loss affects the way they experience subsequent pregnancies and that some of their actions may run the risk of being labeled ‘paranoid’ and ‘ridiculous’ by those who lack the sensitivity to understand. Clinicians need to

realize that their labeling, in particular, has the potential to be both powerful and enduring (Helman, 1990).

Nicky says:

"He was very cross...what are you doing...you're not a breeding machine... he put that seed in my mind"

"It made me so cautious... don't touch cats... "

"DON'T get attached to this because you're not going to have it."

Libby says:

"I just wanted to go home and go to bed, whatever decisions have to be made, they could be made from my bed. I didn't want to WALK, I didn't want to go to the toilet, I didn't want to do ANYTHING... I just wanted to lie in that bed and wait for 9 months. That's what I did..."

Susann says:

"I was glad but the fear was still there. Would I be able to have this baby?"

Participants are telling us that they dread another loss and as a result fear becoming emotionally attached to the fetus, and that they may become almost obsessive and compulsive about their daily activities and treat themselves as an invalid. Keyes (1994) supports these fears, and believes that emotional distress caused by multiple pregnancy losses results in cumulative grief.

Women who were **made to feel special** because they perceived their clinicians actions as taking extra care, found this supportive.

Nicky, Ursula and Libby respectively say:

"...the doctor, the comfort he gave me... said to the nurses... 'special treatment for this one'."

"He was a very good doctor, he was just specially there for women who have had a miscarriage before.

Normal women go to the clinic but there are special women who have to go to him at the hospital".

"...I'll never forget this, he left a fertility patient in the middle of a pick-up to do this suture. He said having been through what he had been through with me, he just wasn't happy to let anybody else do it."

This author speculates that a clinician's efforts at making such women feel special, goes a long way to restoring their sometimes battered self-esteem. However, there appears to be a lack of research on this aspect of care.

Participants in this study articulate their needs immediately following pregnancy loss to be as follows: acknowledgement and validation of their experiences; collaborative decision-making; information; sensitive care and feeling special. *However, the above-mentioned conditions cannot be met unless medical professionals listen to, and understand their women patients.* Therefore respectful listening should be the focus of medical professionals. Doctors should be encouraged to pay attention to patients' stories as a way of hearing their concerns and understandings of their condition. For this to occur, the typical power relationship may need to be realigned with the doctor temporarily surrendering his/her authority to the patient, as storyteller, and assuming the role of the listener (Clark & Mishler, 1992).

3.5 Women's longer-term needs

When medical professionals listen and hear, they will also become aware that womens' longer-term recovery needs vary quite considerably. Although some of these different needs will be discussed briefly, it is most important that doctors and nurses are aware of the fact that patients may have different needs and that they have to listen to, and have respect for what they hear.

For example, some women may be reassured when a doctor is able to **instill hope** by informing them of a favorable prognosis for the next pregnancy where this is possible (Scott, 1994). Others, especially those with unwanted pregnancies, could conceivably react differently.

Nicky recalls being reassured: "...I promise you I'm going to look after you, you will have another child" and Judy reflects: "There was a very good doctor...came and spoke to me and gave me hope."

Susann had no-one to instill hope. She voices a definite need for this when she says: "and no-one even came and gave me hope. I was all alone."

Some participants appear to find it comforting when their clinicians give them hope but feel isolated when this is not forthcoming. Referral to an appropriate source for ongoing

installation of hope could also be of assistance. However, others **have a need not to have hope instilled**. For instance Sandy says: "Being the religious man that he was, he was preaching to me out of the Bible that there would be another chance...I was sitting there looking at this man thinking oh, God just LEAVE ME ALONE – just let me get out of here."

Some women, also have a **need for reconnection** and ongoing processing of the loss, sometimes with others who have had similar experiences and sometimes with expert counselors (DeFrain et al., 1996).

Nicky says:

"If there was a support group that I can speak to some (sic) or listen or say... I know what you are talking about... because if there was a group like that where I could go, it would have been wonderful"

Libby says:

"I made contact with people all over the world who had experiences, similar experiences, worse experiences...The people I was communicating with on the internet knew what I was going through."

"I...joined Compassionate Friends" and "talking... it's therapy for me"

Jackie says:

"It would have helped if there had been somebody to talk to me about the spiritual crisis that I had."

Doctors could therefore play an important role in referring these patients to counselors, other grieving women or support groups (Keye, 1994).

Whilst some women had a need to connect with others and to share their experience, some had a **need not to connect** but rather to work through their thoughts on their own.

Sandy says:

"My problems were mine... the least everybody else knew the better. I have to work through it myself."

"They would come and stand and talk to me ... I didn't want anything or anybody around me..."

Jackie says:

"... that is my way... when I'm in SEVERE crisis, I don't share at all...I will talk about it lots afterwards, but when I am in the middle of it, I withdraw and I carry on as much as possible so that life can be normal."

"...what I wanted was to be alone. I would have liked to have been in a ward on my own ..."

Sonnebloem says:

"I never spoke about it. That helped me a lot."

These women feel that they had their own unique way of dealing with their experience which revolved around having time for introspection on their own. Their needs also must be respected but, once again, their needs will only become apparent when practitioners have listened and understood.

As part of their recovery, some women have a need for remembering and mourning. However, as DeFrain et al. (1996) point out, no rituals have been formalized to recognize such a loss. Bereavement may be complex as there is often no visible child and the death is unexpected and sudden (Lee & Slade, 1996). Society, it seems both trivializes the impact of pregnancy loss(es) and then downplays the need for women to mourn their loss(es). These societal inhibitions may cause further distress and long-term emotional consequences (Lee & Slade, 1996).

Some women in our study indicated that for them, **time to mourn** was important. This is the way that some of them described their mourning: "I cried myself dry" (Ursula); "They allowed me to just stay at home and cry and cry and cry and cry and cry and cry....just let it all out and to be the victim which was you know amazing for me", "time mourning", "...allowing me to get through it at my own pace" (Libby); and "...needed to just lie and sleep and cry and think and write a bit about it" (Jackie).

Libby tells us how helpful it was for her clinician to encourage her to mourn and then to refer her for counseling. She says: "I really believe that the one incredible strength about the gynecologist I have is that he NEVER downplays the emotional side... Don't let anyone tell you that this is the right way or this is the wrong way... your emotional health is as important as your physical health... if you need counseling, I can recommend..."

Keyes (1994) cites studies that show that psychotherapy is an important adjunct to medical therapy. This is especially relevant as, while the medical condition may clear up relatively quickly, the emotional consequences may not (Yudkin, 1989).

While not all women have a need to grieve, they do all have a need for society to accept that they do **not need to mourn but still need to experience relief**.

Sandy says:

"I don't know what they thought of me as a person because I didn't really show any emotion..."

Sandy seems to be concerned that others may have misunderstood her apparent lack of visible mourning. Her fears seem to arise as a result of believing she *should* have been seen to be more emotional at the time of her loss.

Coming to terms with such a loss may also be complex as there are no shared memories with the child (Lee & Slade, 1996). However some participants express **a need for creating memories and for remembering**.

Libby says:

"... it nearly drove me insane that I never saw that baby... " and "Never named them... I regret it now."

"I wanted to do something in their memory...not having graves to go to, I wanted somewhere where I could go where I could remember them... where I could just feel that I could be with them."

Jackie:

"...DID want to see it and I had an incredible need to hold it, it was like a wild animal need to hold it."

"... this urge became unbearable...I started every day to...put a little pillow in the baby blanket and to hold the blanket with the pillow inside it. I HAD to do this ... It used to ease something in me"

"I visit that little grave... take flowers ... remember her birthday and wonder what she would be like"

Other participants say: "I wanted to see what it looked like on the screen" (Ursula); and "...cross about, is that I never asked was it a boy or was it a girl" (Nicky).

These women seem to be indicating that not seeing their child and in some instances not knowing the sex of the child(ren) or not naming it/them, caused emotional distress whereas having a grave or memorial was helpful. De Frain et al. (1996) found that after a mean of 5,4 years patients still thought of their child an average of 11,3 times per month.

However, for some women, the memory was something they **needed to forget**

Judy and Sandy respectively say:

"No...I didn't want to see it again."

"I didn't want to speak about it....I just wanted to take a rubber and erase it out of my life."

Unlike previous participants, these women tell us they have a need to let this memory go or to actively try not to remember. Research in this area also appears to be lacking which may indicate that society again dictates that women *should* want to remember. However when doctors listen, they will realize that women may have different needs in this regard and should refer to appropriate caregivers when indicated. These women feel that they had their own unique way of dealing with their experience which revolved around having time for introspection on their own. Their needs also must be respected but, once again, their needs will only become apparent when practitioners have listened and understood.

Beutel et al. (1996) and Layne (1990), found that some women **search for meaning** in this seemingly inexplicable loss.

Libby says:

"It was almost like a lesson for me... that you don't just get what you want and the way you want it..."

Jackie says:

"...affected very deeply my understanding of God... it was the beginning of a COMPLETE spiritual revolution... looking back I really do believe that it was part of the plan... it was meant to be..."

"Looking back now.... Maybe it was a blessing (inaudible) although I didn't think so at the time."

These participants tell us that their loss could be understood as a lesson, a blessing and also as the impetus for transformation. When they were able to make meaning out of their loss, it was seen as being helpful. For those searching for meaning, a referral for psychological help could assist them with integrating this experience into their lives.

Women's longer-term needs are divergent: a need to have hope instilled, to reconnect, to mourn, to create memories and remember or not to. For some women, searching for meaning is also helpful. Regardless of what those needs are, however, it seems imperative that healthcare workers ask the women what they need and do not merely make assumptions.

4. CONCLUSION

When a clinician is sensitive, caring and skilled in helping their patient through the potentially devastating time surrounding pregnancy loss, he/she could play a critical role in helping such women on the road to recovery and thus prevent long-term emotional problems (DeFrain et al., 1996; Johnson, 1996). However, in a review of literature on miscarriages, Lee and Slade (1996), found that 'there appears to be a general dissatisfaction with many aspects of management and care, both at primary care level and with hospital services' (p.239). Reader (1989) believes that every gynecology department needs to look at the way it is handling the problems of pregnancy loss.

Mishler (1984) makes the point that modern medicine ignores many important therapeutic aspects of the doctor/patient relationship. Participants in the current study clearly felt that hospitals should provide for more than just physical needs. For instance Judy says: "... they must treat you medically but also attend to you inner emotions but this isn't done in the hospital." Medical personnel too often believe that when the physical symptoms have cleared up their job is over (Yudkin, 1989). Judy, says it most succinctly: "...if they don't see any blood then there is NOTHING wrong with you."

The current study was an attempt to determine not only how medical professionals actually shape the experience of pregnancy loss, but to also make suggestions regarding how they can shape these experiences in more positive ways. This was done by exploring how women understand and feel about pregnancy and pregnancy loss and what women's emotional needs are following such losses.

The current study firstly found that women have very different feelings about pregnancy and pregnancy loss. These feelings are at least in part determined by whether the pregnancy was wanted or not. The second very important finding of this study is that, regardless of whether pregnancy loss is experienced as devastating or as a relief, all women's immediate needs from medical personnel are remarkably similar. These

immediate needs, it was found, are all related to the fact that women feel that it is of crucial importance that their emotional experience of the loss is taken seriously by medical personnel and thus validated. For medical personnel to fulfil these needs, it is imperative that they understand the contexts within which women experience pregnancy loss. The decisive factor then is whether women feel that they have been heard AND listened to.

For this to happen it seems that clinicians need to be able to discard their own theories and assumptions and create a safe environment where their patient feels in control. This creation of safety within the medical context, revolves primarily around respectfully encouraging women to tell their pregnancy and loss stories and then acting in caring and sensitive ways. It was also found in this study that if clinicians do fulfil this first need for attention and validation, they will also be sensitive to the fact that the longer term needs of women vary considerably. If they discard their own assumptions and values, they will, for instance, find out that while some women need to mourn their loss, others do not. Some women need to be given hope, while others do not need that. There are women, who, in the long-term need to connect or reconnect with others, but there are also women who need to be by themselves. Physicians and nurses should be trained to know when such needs necessitate referrals to other support forms such as psychologists, spiritual counselors, support groups or to other women who have had similar experiences.

To summarize then, it can be said that this study found that after pregnancy loss, women's immediate needs from medical personnel are remarkably similar. Paying attention to those short-term needs of validation will make medical personnel sensitive to the very different needs that these patients may have in the long-term (see Appendix 7 p.65) for summary).

As medical professionals are often pressed for time and appear not to have the necessary training, it seems that a referral for psychological debriefing and assistance would be helpful in improving the long-term psychiatric health of these women. One participant in the Speraw study (1994) says the following about medical personnel: 'If they can't

provide emotional support, that's okay, but they should at least make some arrangements to have someone else provide it' (p. 213). Lee and Slade (1996) cite research where 6 months after their loss, women who had received initial psychological counseling, showed only a quarter of the rate of psychiatric disorder than women who had not receive the intervention. Furthermore, Mann (cited in Keye, 1994) found that 'before treatment with psychotherapy, 91% of the 290 pregnancies in 70 women ended in a miscarriage. After therapy, only 19% of the 101 pregnancies miscarried' (p.676). Other studies also support the view that women having experienced pregnancy loss should be referred for counseling when their needs are more complicated (Lee & Slade, 1996; Leppert, 1984).

Although this study clearly delineates some of the ways in which medical personnel can help to provide a context within which women can process their experiences of pregnancy loss, it has very specific limitations and raises many new questions.

Because this was an exploratory study focusing on the medical context, it was impossible to discuss in detail exactly how dominant discourses of gender, class, religion and culture impact on the way in which women and medical personnel construct the experience of pregnancy loss. In future studies, the data of this study can be used to explore in detail how such discourses can be traced in the narratives of individual women. In this paper it was emphasized that there are differences in how these experiences are constructed, but there no attempt was made to discuss how such constructions come about and how they function. Because the focus was ultimately on women's needs and the similarities of the most basic needs, it was not possible to focus in depth on the very interesting differences that do exist in processes of meaning-making.

Even if this is not the focus of the study, the current study highlights once again how pervasive dominant gender discourses are and how they impact specifically on women's experiences around reproduction. This study seems to underline the assertion that it is around issues of reproduction where women are at a substantially higher mental health risk due in part to societal expectations.

If research on the impact of pregnancy loss on women is scarce, research concerning the partners (male and female) of such women is almost non-existent. It is important to study not only the impact on pregnancy loss on them, but also to study how their responses can shape the experiences of women going through pregnancy loss.

As in all qualitative research, the impact of the researcher and the role that she played in the interviews, is very important. Again, due to lack of space, the researcher's subjectivity could not be the focus of attention. It will be very interesting to study these interviews by looking at them as being co-constructed by participants and interviewer, each operating within her own social contexts.

Although there was an attempt to include women from as many different contexts as possible, this was not an attempt to generate a representative sample that could yield generalizable results. Qualitative studies are seldom big enough to be able to generalize results. Very important groups of women were not represented for example African women, women with lesbian partners etcetera. This was rather an attempt to give a voice to women with varied experiences and varied backgrounds. It remains remarkable then that all of the participants, regardless of background or experience, do articulate important common needs after pregnancy loss: being listened to, being validated and receiving collaborative and sensitive care.

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Appendix 1

Demographic details

The purpose of this questionnaire is to obtain details about your life.

Name:

Birth date:

Age:

Address:

Present occupation:

Relationship status: (circle one): Single Engaged Married Separated Divorced Widowed Remarried
Living with someone Involved with someone

PERSONAL AND SOCIAL HISTORY

Place of birth:

Siblings: Number of brothers: Ages:

Number of sisters: Ages:

Your position in the family:

Mother: Living: If alive, her age:

Deceased: If so, how old were you at the time:

Occupation:

Father: Living: If alive, her age:

Deceased: If so, how old were you at the time:

Occupation:

Religion: As a child:

As an adult:

Is religion important in your life:

Education: what is the highest level attained:

Underline any of the following that applied during your childhood and adolescence

Happy childhood	School problems	Medical problems
Unhappy childhood	Family problems	Alcohol abuse
Emotional problems	Behavior problems	Legal trouble
Strong religious convictions		Drug abuse
Conservative/Liberal upbringing		
Others:		

DETAILS AT TIME OF PREGNANCY LOSS/LOSSES

Age:

Relationship status:

Children:

Name:	Age
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Type of work at the time:

Yourself:

Your partner:

Did you have a regular doctor or gynaecologist you were consulting?

Would you consider yourself to have been more liberal or conservative in your outlook?

How would you have described your social class? middle class: working class

CURRENT INFORMATION

Relationship status:

Children:

Names:

Age:

Type of work:

Yourself:

Partner:

Have you ever received psychological counselling or been on any psychiatric medication (e.g. Prozac).

Please give details:

Thank you for your time and co-operation

Appendix 2
Informed consent form

SOUTH AFRICAN WOMENS EXPERIENCE OF PREGNANCY LOSS

Dear Participant

We would like to request your participation in a research study examining women's experience of prenatal loss through either miscarriage or stillbirth. We are interested in learning about how women experience such a loss.

If you are willing to participate in this study, we would like to conduct a face to face interview with you, which would take approximately one hour. This interview will be tape-recorded. A female researcher who is a clinical psychology master's student will carry out the interviews. The interviews will be held at a venue convenient to you and at a time that suits you.

In the interview, questions will be asked about your miscarriage/stillbirth experience e.g. what actually happened, what support you received, how you felt at the time and how you feel now.

Some of these questions will be highly personal and may bring back some difficult memories. However, please be assured that you can stop the interview at any time or that you can refuse to answer specific questions during it. You are also free to discontinue participation at any time. Should you choose to do so, you can request that all of the data collected about you, including tapes and transcriptions of tapes, be destroyed and they will be.

Should you find questions asked in the course of the research interview bring back painful or difficult memories and you would like to talk to someone about your feelings, we have a list of helping services you could contact.

To ensure confidentiality of the research material, no names will be placed on interviews or forms. Each participant will be given a code name and a list will be kept showing which participant corresponds to which code name. The list will be kept in a locked safe. Only the researcher and her supervisor will have access to any of the data, including the tapes and transcripts, which will also be stored in the above-mentioned safe. Thus all information will be kept confidential. Reports about the study, including articles, will not mention any real names. Descriptions of any individuals will be disguised, so that they will not be recognizable to anyone else reading the study. Thus, there will be no way to tie in any piece of information

collected by the study with any specific individual or family. As such information about women's lives is valuable, the tapes will be kept as long as the researcher is pursuing this area of research. Thereafter, the tapes will be destroyed, along with the list containing names and code names.

If you participate in the study and would like to receive a copy of the final study, please note this on the informed consent form below.

If you are interested in participating in this study, please read the following statement and sign below.

I understand that participation in this study is voluntary and am aware of the possible risks, benefits and inconveniences associated with my participation. I recognize that I am free to ask questions, to refuse to answer questions, and to terminate the session at any time. I also understand that if I have any questions or problems concerning this research that I should contact the principal researcher, Cari Corbet-Owen at 8522234 (after hours) or her supervisor, Dr. Lou-Marie Kruger at 8083460 (office hours only).

Signature of participant

Date

.....Yes, I would like to receive a report of the study's findings

Address:

Appendix 3

Possible interview questions

YOUR PREGNANCY /IES AND YOUR EXPECTATIONS

- Tell me about your pregnancy/ies
- How did you discover you were pregnant?
- What was your initial reaction to your pregnancy?
- How did being pregnant change the way you thought about yourself?
- How did being pregnant change the way you thought about your role?
- What did being pregnant do for your identity as a person?
- Did being pregnant change your relationship with others? (husband, mother, siblings, friends?)
- Tell me about your feelings towards your changing body
- How did you think your life would be different after your baby arrived?
- Did the way people treated you change while you were pregnant? If so, how?
- What plans if any had you made for the arrival of your baby? (e.g. Buying clothes, choosing a name, preparing the nursery, resigning from a job)
- Do you have any particularly happy or sad memories of your pregnancy?

CIRCUMSTANCES OF THE PREGNANCY LOSS

- How did you first realize there was a problem with your pregnancy?
- What was your first reaction?
- Who did you turn to for help
- How did your partner react?
- What were the helpful reactions of others (family and friends)?
- What were the hurtful reactions of others (family and friends)?
- How did these affect you?
- What support did you receive from others around your pregnancy loss?
- Was there any major event that stands out about that time

YOUR EXPERIENCE WITH THE MEDICAL PROFESSION

- How would you describe your experience with any medical institution or professional?
- What, about your exposure to the medical profession helped/hurt?
- How would you change your medical experience (assuming you could?)
- What was most helpful in helping you recover?
- What hindered your recovery the most?
- What explanation were you given for your loss? Were you satisfied with it? Why?
- How did you feel about your contact with the medical help you received (both physically and mentally?)
- How would you describe your relationship with your doctor / gynecologist then and now?
- What ward were you put into? What were the advantages /disadvantages of being in that ward?
- How did it feel to leave the hospital with empty arms?
- How did you feel when the medical bills started arriving?

CONTACT WITH YOUR BABY

- Did you have any contact with your baby? If so how?
- Do you have any mementos of your baby (sonar scans, pictures, foot/handprints?) and how did it happen that you have them?
- How were you able to say goodbye to your babies?
- How was your medical experience good or bad in helping you deal with your loss?

GOING HOME

- How did you feel arriving at home?
- How did you experience seeing other pregnant moms / newborn babies
- Describe your first month after your loss
- How did you go about re-constructing your life?

LOOKING BACK ON YOUR LOSS

- What are your feelings like now after your pregnancy loss
- Did you feel different about yourself after the loss? If so, how?
- Did you feel differently towards your partner or your relationship after your loss? If so, how?
- How did your loss affect the way you felt about falling pregnant again?
- How did your loss affect your following pregnancy experiences?
- If you reflect on your pregnancy loss, what is it that you think caused you the most distress?
- What advice would you give somebody in the same situation?
- What advice would you give hospitals, nurses or doctors in their attempts to help women suffering a pregnancy loss?
- How do you think about your lost child now? (e.g. do you refer to him/her by name? Is he/she considered as part of the family? How often do you still think about this child?)
- If you had that same pregnancy over again, is there anything you would do differently?
- If you had to have the same loss again, is there anything you would like to have handled differently?
- Do you feel you have gained anything from the experience?

Appendix 4

Simplified Transcription Symbols

Symbol	Example	Explanation
[I: quite a [while L: [yes, it	Left brackets indicate the point at which a current speaker's talk is overlapped by another's talk
=	I: how did you= L: =devastated	Equal signs, one at the end of a line and one at the beginning, indicate no gap between the two lines
(.2)	Yes (.2) um	Numbers in brackets indicate elapsed time in silence in tenths of a second
(.)	I was (.) sad	A dot in brackets indicates a tiny gap, probably no more than one-tenth of a second
_____	He <i>was</i> upset	Underscoring or italics indicates some form of stress, via pitch and/or amplitude.
:::	Deva:stated	Colons indicate prolongation of the immediately prior sounds relative to the surrounding talk
WORD	How DARE	Capitals, except at the beginning of lines, indicate loud sounds relative to the surrounding talk.
()	he was ()	Empty brackets indicate the transcriber's inability to hear what was said
(word)	he went (there)	Words in brackets are possible hearings
{ }	so sad {crying}	Parentheses contain transcriber's descriptions rather than transcriptions

Appendix 5

Coding categories

- (1) Meaning of the pregnancy
- (2) Meaning of the loss
- (3) Seeing baby as real
- (4) Needs after loss
 - (4a) Religious
 - (4b) From partner
 - (4c) In General
 - (4d) From medical professionals
- (5) Feelings about pregnancy
- (6) Feelings after loss
- (7) Patients beliefs about doctors
- (8) Medical Professionals' assumptions about patients' needs
- (9) What helped/ coping resources
- (10) What hindered
- (11) Blame of others
- (12) Blame of self
- (13) Womens' knowledge about themselves and their bodies
- (14) Nature of the couples relationship
- (15) Medical Context
- (16) Religious Context
- (17) Long term consequences
- (18) Regrets
- (19) Financial Context
- (20) How subsequent pregnancies were affected
- (21) What society demands/expects
- (22) Remembering days and times
- (23) Who they first turned to for help
- (24) Thoughts women have about themselves

Appendix 6

Coding 'memo' for Libby

(1) Meaning of the pregnancy

- ...I had wanted it from the day I got married (1.9)
- It was just something I wanted, it was something I have wanted for a long time... not having analyzed it, just something I wanted to do, I wanted to have a baby, I wanted to have D's baby and finally after a long struggle, it had happened. So it was not something that I had thought through or planned or anything, just something I wanted to do and I DID IT. (1.12-15)
- ...just DID it ...It was just something I wanted and I just did it. Never thought about how our lives would change at all. (1.18-19)
- I enjoyed the excitement revolved, that revolved around any pregnancy. People do kind of treat you a little bit differently, maybe make you feel a little bit special... you know somethings changing somethings happening, there's an exciting thing like coming. And people do treat you differently and I certainly enjoyed that. I mean it wasn't something I was looking for (2.7-11)
- Ja, the pregnancy was definitely important to me. I've always looked forward to being pregnant. ... I dunno for what reason, I just loved it, the idea of being pregnant (2.23)
-the second I found out I was pregnant then that was a baby and that was a part of us (5.5)
- I just wanted them to do whatever had to be done in order to save that pregnancy. (7.19-21)
- My first question was 'am I still pregnant is the baby still ok?' (7.27-28)
- ...' Whatever you do just make sure that this baby is fine.' I didn't care what they did to me as long as the baby was fine. (7.25-26)
-as long as the baby was fine, I was fine. (8.8)
- As long as I am pregnant and I'm going to have the baby, it's fine. There were days when I literally crawled to the phone when I was so sick (15.67)
- I was pregnant, I was pregnant and as far as I was concerned there was a baby coming and I allowed myself to become fully involved in that (16.12-13)
- When I found out that it was twins it gave me a false perspective, I suddenly latched onto the perspective that I had had to lose those two babies because I was going to have two more. Crazy. (16.20-21)
- ...it wasn't important to him it was important to ME. (24.6)
- The minute that I was not on fertility treatment it was an absolute I couldn't handle it it was like a daily obsession what do I do today to have a baby
- To me, it was just something I had to do (26.17)
- I remember saying to D if there's a choice let them live and let me die (29.26-27)

- If anything ever goes wrong and you have to choose between me and the babies let it be them. I don't want to live if I can't have these babies (29.31-32).
-if you have to choose I do not want to live if the babies die (30. 3-4)
- ...all I wanted was for them to live. It didn't matter in what condition or in what state or what we were going to have to do, you know. People were kind of saying you're going to have two not helpless babies, but two children with special needs and they'll like take up your whole life and can your marriage stand that and I DIDN'T care. They were alive and I got far enough for them to be born alive and now they just HAD to survive, it didn't matter in what condition. (32.14-19)
- I felt like a whole person (35.28)
- ...it was MY baby (36.3)
- THIS had been my mission in life (36.18)
- ...THAT baby was meant for us and it couldn't, all my miscarriages and all the heartache was better for me (36.20-21)
- I've always felt that I would be a good mother always known in my heart that I would have been a capable mother that I would it would be the one thing in my life that I would be good at (36.30-32)
- ...it's just the one thing in life that has always felt right for me (36.32-33)
- ...'you were born to be a mother' TOTALLY I mean she's like 3 days old and it's the most natural thing in the world to you (37.14-15)

(2) Meaning of the loss

- I was a Daddy's girl and it just made this experience a little harder to accept because my father couldn't be the hero there was nothing he could do to change it. It was just hard to accept that there was something I wanted that I couldn't have or that I had to wait for or that I had to work for that I had been given and now it had been taken away again (6.2-5)
- I just thought it was maybe a lesson I had to learn and I'd learnt it and I was now ready to have my baby. (6.22-23)
- ...every loss was making me more and more determined to have a baby (16.1)
- ...I think the actual baby had become almost a secondary issue the pregnancy and getting to term was becoming more and more of the main issue (16.2-3)
- I think that I'd even stopped thinking about the baby that was going to be the end product. You know at that point what had become the whole issue was getting pregnant and staying pregnant (16.5-6).
- The fact that I had lost the babies wasn't important the fact that I was ALIVE was and everybody was making such a fuss about it (21.1-2)
- ...that I would never have a child didn't even cross my mind yet. It wasn't the end of the road for me (23.15-16)
- In my mind it wasn't over, not by a long shot. I was still I still had a uterus and I was still capable of falling pregnant and that was all I needed (23.16-17)

- I didn't want to live the rest of my life knowing that I was the reason that he didn't have a biological child (24.9-10)
- I just didn't want to go through my life the rest of my life knowing that D didn't have a biological child because I couldn't give it to him (24.13-14)
- ...but it was just something the last thing I had to do before I could actually accept right now we can start the adoption procedure (26.18-19).
- I just wanted to die. I didn't care what happened (29.20)
- I didn't give up totally I still had an ovary well I still have 2 ovaries left and I was still thinking well I can still have a surrogate mother and have a biological child (35.17-18).
- ...I would never have stopped... I would never have stopped (37.17)
- ...I don't think that I've ever really considered myself as a failure as a woman ... wev'e always had a good sex life (37.19-21)
- I've never really felt that I've failed as a woman it's just something that my body failed but it was out of my control. I never felt that I had any control over it (37.21-22)
- It was almost like a lesson for me. I almost feel like I had it so easy my whole life I was sheltered I never leant any lessons it's almost like it was a fucking hard lesson and it was a damn long road I had to go through but almost like something that I HAD to experience that you don't just get what you want and the way you want it (37.23-26)
- I've never really felt that I've failed as a woman because I look at myself now as a mother and I KNOW I'm a good mother (37.27-28).

(3) Seeing baby as real

- ...I ran out and bought baby clothes the minute I found out I was pregnant (2.16)
- ...COULDN'T wait for that day when I could walk in and actually buy something and I think I probably did in on the same day that my pregnancy was confirmed. I went shopping (2.19-21)
- ...the second I found out I was pregnant then that was a baby and that was a *part* of us (5.5-6)
- ...rushed off to the shops and went shopping (6.19)
- ...I don't think I don't think if you haven't been through that you can never know you know what that feels like (13.14-16)
- ...there was a baby coming home. D had hand-built furniture himself he'd built the compact the bookcase for the babies room which I had sat and hand-painted which was great for me while I was pregnant. I had been knitting jerseys my mother had been knitting already but that stage. I was fully prepared and fully equipt for that baby (13.20-23)
- If I can't have THESE babies it wasn't even a case anymore of having a baby. I HAD developed an incredible bond with these two. I knew they were girls (29.31-33)
- ...these babies were a complete reality in my mind (29. 34-35)
- I felt far more like I knew them because I carried them before they were born (35.7-8)

(4) Needs after loss

- **(4a) Religious**

- **(4b) From partner**

(See (14) Nature of partner's relationship)

- **(4c) In General**

- ...but my husband and my family well my father kind of had control there. ' Lets focus on something else (4.24-25)
- ...encouraged me to get back to work so that I could start focussing on other things (4.26-27)
- I think I would have gone INSANE if I hadn't seen them (20.5)
- ...EVERYBODY was concentrating on ME (20.14)
- ...a great source of comfort in the internet ... e.mailing ...going into sites that revolve around women and miscarriage and made contact with people all over the world who had experiences similar experiences worse experiences I never went for conseling after that one (21.5-9)
- ...joined Compassionate Friends (21.11)
- ...found the internet an incredible source of comfort (21.13)
- The people I was communicating with on the internet knew what I was going through. They had been through similar or worse or better or not so bad or had had multiple losses. They knew what I was going through they didn't even feel like strangers to me. I just I found it so comforting to be able to talk to somebody who knew what I was feeling (21.16-19)
- I really felt that it needed to be acknowledged. I felt that by ignoring it people were saying that they were never really born and they never really existed and drove it really used to frustrate me. I remember going through a stage where I wanted to do something in their memory. Not you know not having having been cremated and not having graves to go to I wanted somewhere where I could go where I could remember them. I remember contacting the botanical gardens wanting to donate a bench or having a plaque put up or something where I could just go where I could just feel that I could be with them (22.18-24).
- I UNDERSTAND that some people just don't know what to say and they don't know how to handle it and they just ignore it but that was worse for me (22.27-28)
- ...just ACKNOWLEDGE that it happened. People tried to pretend that it didn't happen which I found very difficult (23.1-2)
- ...stopped going to any form of baby shower, tupperware parties, kitchen teas. I couldn't be in a room just with women. The topic of conversation inevitable lands up being about babies or pregnancy (23.4-6)

- ...stopped going into any kind of baby shops or shopping centres where I would even have to walk past a baby shop (23.10-11)
- ...packed everything. I refused to give anything away. I still haven't (23.13)
- ...I don't have a problem talking at all it's therapy for me (38.11-12)

- **(4d) From medical professionals**

(see (15) Medical Context)

(5) Feelings about pregnancy

- ...Over the moon over the moon (1.9)
- It was a RELIEF to finally fall pregnant (1.10)
- It made me relax you know after the stresses of the build up of the fertility treatment (2.2)
- I didn't have to worry about what day of the month this was ... things lightened up a little bit (2.3-4)
- ...happy to be pregnant (2.12)
- I just LOVED it, the idea of being pregnant (2.24)
- ...very relieved that it wasn't going to take 18 months to get there again. I was very confident (6.17)
- ...I was very hopeful (6.18-19)
- ...I was totally confident that the next pregnancy would be fine (6.28)
- ...as long as the baby was fine I was fine (8.8)
- ...confident that this pregnancy was now fine (8.11)
- I was feeling fine I was looking Swell by that stage, feeling on top of the world. I mean I LOVED being pregnant I LOVED my stomach I LOVED EVERYTHING about it. I loved being able to feel the baby kick I loved the whole experience of pregnancy (8.15-18)
- ...fully confident that that pregnancy was going to go to term and that there was a baby coming home (13.19-20)
- The fact that I enjoyed being pregnant so much was not the next time because from then on pregnancy became a nightmare (16.8-9)
- ...It was just mindblowing. I was over the moon, I was over the moon (17.11-12)
- ...its unbelievable (26.30)

(6) Feelings after loss

- Terrified, ABSOLUTELY TERRIFIED (3.14)
- ...felt like my world was falling apart (3.16)
- ...heartbreaking (4.14)
- ...devastated I mean I REALLY REALLY wanted this baby (4.30)

- I really couldn't believe that it could go wrong (4.31)
- I was pretty devastated I really wanted that baby (5.3)
- I was devastated when I lost this pregnancy (5.6)
- Not that it affected me terribly (5.24)
- TERRIFIED absolutely TERRIFIED (7.19)
- ...scared not terrified but scared, certainly apprehensive (8.24)
- We had a lot of time to think about it and I don't think it actually hit home you know that I was actually going to lose this baby (10.3-4)
- This baby wasn't going to survive but I was totally calm (10.6)
- I can't remember to be honest. I can't remember what I felt when that happened (10.27)
- I didn't want to give birth to the baby. Once I knew that I wasn't going to have a baby to hold afterwards I didn't want to give birth to the baby. I was quite happy to be put to sleep and for it to be over when I opened up my eyes again. You know I'm quite vague about the emotions then I just I mean I remember kind of feeling like I was on a roller coaster like it wasn't me but it was me but it couldn't have been happening to me (10.33 –11.5)
- ...I just couldn't believe (11.28)
- ...I remember thinking I don't know WHAT to do I dunno I was terrified to see the baby because I didn't know what to expect but at the same time I had the curiosity because I had this visual of this little D with long hair and a ponytail (12.5-7)
- You know the people around me were incredibly supportive and understanding and whatever but nobody knew what I was going through (21.19-20)
- I had terrible feelings of guilt about D not being able to have a child of his own (24.1)
- (nurses name) kept saying to me 'it's over she's gone' and I kept saying 'no ways she is going to live' (34.22-23)

(7) Patients beliefs about doctors

- ...accepted that whole-heartedly (5.11)
- ...I really believed, I had accepted the gyne's explanation (6.17)
- ...said she didn't think we should see the baby. And we I accepted her decision (12.10-11)
- I don't really understand what the nurses motivation was coz the baby was perfectly normal, it was just very small (12. 24-25)
- ...I didn't feel that he could have changed it (15.20)
- ...I believe... I have TOTAL faith in them as doctors and as human beings (19.21-22)

(8) Medical Professionals' assumptions about patients' needs

- ...I don't feel that she had any right to make that decision for us (13.14)

- ...when he left the hospital that night to go home went to her and said that he would like to see the baby and she wouldn't allow him to see it. SHE at that point had made her decision that we shouldn't see it and she actually said no she's not going to show him the baby (13.9-11)
- I FORCED them to let me go to the funeral you know they didn't want me to go and on the Friday, but I said there is no way you are keeping me in this hospital while you bury my baby (34.4-6)

(9) What helped/ coping resources

- ...D was with me the whole time which was a major source of comfort to me (4.17)
- I went back to work pretty quickly (4.23)
- ...allowed me to just let it all out and to be the victim which was you know amazing for me (11.18).
- I kept visualizing this tiny little person boy person with long hair with a ponytail (11.31-32)
- ...it really drove me nuts that I didn't know what they child looked like (12.16)
- ...spent the most time mourning because everyone allowed that (14.16-17)
- ...just stay at home and cry and cry and cry and cry and cry and cry and cry which I did probably for a month or two Then I got on this mission of finding a photo of that baby and became all consumed with that. Then once I was physically over the whole thing I went back to work and I talked to everybody anybody who was willing to listen heard my whole drama. That was my therapy (14.19-23)
- People were unbelievable... my mother was UNBELIEVABLE. She cried with me and it was like she had lost a baby (15.4-5)
- We went off to England to visit D's sister and while we were there she offered to surrogate for us. That was 1994 and THAT then became my focus you see I was then happy to stop trying. You see I always felt that I was ok and I could handle everything I had been through as long as I was doing something constructive. And being on fertility treatment to me was constructive it was a means to an end. I was doing something to try and rectify the situation to try and fall pregnant to try and have a baby to try and do whatever. As long as I was on fertility treatment I felt that I was doing something. The minute that I was not on fertility treatment it was an absolute I couldn't handle it it was like a daily obsession what do I do today to have a baby. As long as I knew that I had to go for an injection I had to take a pill or I had to have sex or I had to do whatever doing something. constructive. But once she had offered to surrogate I was happy to stop with fertility and I was happy to then focus all my attention that way (24.22-31)
- ...but I I don't know when I saw Jamie to me it put all the losses into perspective I wasn't supposed to have had a child of my own because I would never had Jamie and I would have missed out on so much for not having Jamie (36.26-28).

(10) What hindered

- A lot of people tend to treat early miscarriage very lightly. They say things like 'it wasn't a baby' and that kind of nonsense (5.4-5)

- ...it still bothers me. I still have this vision of this little D with this ponytail in his hair. I don't think I every really did come to terms with that and it REALLY was a very difficult thing for me (12. 19-20)
- ...it really drove me nuts that I didn't know what they child looked like (12.15-16)
- I remember people saying hurtful things like 'A miscarriage isn't the same as losing a baby.'....'you didn't know the baby and thank God you hadn't got to hold the baby or see the baby'... to me they were just the most mindless comments. Or 'your'e still young and youv'e got plenty of time and don't worry there will be plenty of others babies'... like one can replace another (14.25-28)
- ...'I've been your surrogate Mom while you haven't been able to'. She was INCREDIBLY attached to the babies already. I almost felt resentful for that comment. I didn't like the fact that she had felt her role to be that of mother (30-25-27).

(11) Blame of others

- I was very angry with her (13.7)
- You wonder about the doctors. Did he do everything he could (15.14)
- I did ascribe a small portion of blame must say. On the last try she didn't stay in bed like she was supposed to the first try she did for like 5 days and I did everything for the baby, I took her to school bathed her she did NOTHING. The last try it just so happened that her husband got a break and him and her son came to South Africa the day after the transfer. She was up having dinner parties and shopping and she'd been told she wasn't allowed to sleep with her husband which was TERRIBLY hard for her I mean she hadn't seen him for 4 to 5 months or whatever. And I don't know I mean I can't say with certainty whether they didn't but I just feel that she didn't give it as much effort as I would give it if it had been MY body that I was using I would have used a fly-swatter to keep D away from me. NOTHING would have got me out of bed for 10 days. You know what I mean? So there was some portion of blame laid there (25.21-32)

(12) Blame of self

- You wonder to yourself should we maybe have not had the stitch put in should we have rather just left it and let nature take it's course (15.12-13)
- ...I didn't want to live the rest of my life knowing that I was the reason that he didn't have a biological child. I didn't think I could face it (24.9-10)
- ...I just didn't want to go through my life, the rest of my life knowing that D didn't have a biological child because I couldn't give it to him (24.13-14)

(13) Womens' knowledge about themselves and their bodies

- I said this is no wind. And I started to SCREAM (28.24)

- Get Dr. E, something is wrong ... I knew something was going wrong (28.28-29)

(14) Nature of the couples relationship

- ...D was with me the whole time which was a major source of comfort to me (4.17)
- ...it brought D and I closer together. D was very sympathetic and very understanding, very supportive which was good for our relationship (5.13-14)
- It wasn't something he ever suggested or something he ever pushed for it was he was just merely co-operative and quite happy to have a child if that was what was going to be. But certainly it wasn't an issue for him (5.19-21)
- I certainly don't think it affected him as badly as it did me (5.24)
- ...D was sitting there and everything was calm and we were laughing and talking and I don't know (10.8)
- I just remember D being there for me ALL the time. D NEVER left my side. And that was an incredible source of comfort for me the fact that I was ok if he was ok (11.5-6)
- ...he started to cry and that shut my emotions down completely. I had been crying all the time and you know whatever and as soon as he started to cry I my tears dried up and I suddenly felt like I had to be strong. He fought it and he pulled himself together but I suddenly realized that I wasn't the only one who was going through this. You know I just he was there for me TOTALLY 100% emotionally physically I mean he never closed his eyes (11.8-13)
- ...he NEVER left my side... he turned me over every hour. That was that really I believe that if I had had a husband who was more emotional than he was I would have had to be stronger. He allowed me to just let it all out and to be the victim which was you know amazing for me (11.16-18).
- ...if we wanted to see it and D was with me and he said he would do whatever I decided. If I wanted to see the baby he would be there with me and we could see the baby together but if I didn't want to see the baby that was fine (12.3-5)
- D had this thing to have photo's taken without even discussing it with me (12.22)
- ...he should have fought (13.12)
- ...D had put flowers in the house and he's put welcome signs all over the place (13.28-29)
- ...D was INCREDIBLY supportive, incredibly patient at allowing me to get through it at my own pace... he allowed me to keep talking and going over the same thing. Why it happened and what we could have done differently and all those sort of things which helped tremendously (15.6-9)
- ...he had them cleaned up and brought to me and had taken photo's of me holding them (20.1-2)
- Even D after that miscarriage switched off. You know by the time I was home and I was on the road to recovery it was only like a month or two and he said enough he doesn't want to come home to tears anymore and I must get it together and put it behind me and we must start focussing on what our life is going to be. There aren't going to be children and you know. I even reached a point where I couldn't talk to HIM about it (21.21-25)

- ...I think he was UNBELIEVABLE (sic) caring and it brought us closer again (21.27-28)
- Each of these incidents kind of renewed that again reminded us of what we've got and what we've got in each other and that was very comforting for me to just be close to D and know that when he climbed into bed next to me all he wanted to do was to hold me and just that whole thing that strengthened our marriage at that time. By shutting me off or saying that he doesn't want to talk about it anymore (.) NOW LONG TERM there are a lot of issues that remain unresolved which I believe is part of the reason that we have reached the point we have in our marriage now.....separation (22.1-9)
- ...I still needed to talk and that he wasn't willing to talk anymore and the next pregnancy and the next miscarriage there was a lot of talking HE should have done and didn't do and it all these things have almost built a wall between us (22.10-12)
- ...he didn't blame me (24.10-11)
- Having a baby was never that much of an issue for him and it was certainly never going to be the reason that he would leave (24.16-16)
- ...it was like a big game confusing him (30.1)
- ... D got the video machine and taped the babies took photos and everything so I was seeing footage (30.16-17)
- ...we'd both felt the same pain and everything like that but I didn't think that it really hurt our relationship. Its only now with this whole separation that I do realize how much damage it did do (34.27-29)
- I know that he doesn't blame ME (35.7)
- ...he does blame me for pushing the subject. He was happy just to accept that we weren't going to have children after the second miscarriage already but I had to force the issue and I had to risk my life and I had to put us through all that hell. He blames me for that for pushing the issue too far. You know he doesn't blame me for them dying (35.9-13)
- ...D kept saying to me he can love any baby and I COULDN'T BELIEVE that. I didn't matter to him WHERE the baby come from (36.12-13)

(15) Medical Context

- He examined me and said no there is still a heartbeat.... I realized that it didn't HAVE to mean the end of the pregnancy (3.19)
- ...give me a bit of hope and I'll clutch it like I'll GRAB onto it and I'll HANG onto it for dear life (3.21-22)
- ...ABSOLUTELY wonderful totally sympathetic had all the time in the world to sit and explain and discuss and let us ask questions (4.13-14)
- It wasn't a case that I was, that I became overly concerned about my ability to carry a child to term... gyne had explained early miscarriages (5.6-8)

- Once the gyne had given me you know the information that it's usually a once-off occurrence and everything should probably be fine in the next pregnancy, I accepted that wholeheartedly (5.25-27)
- I was warned of the possible risk of miscarriage with surgery (7.16)
- I phoned my gyne at home. He told me to come straight into labour ward (9.9)
- ...plan of action that was discussed (9.15)
- ...D and I were given the options (9.22)
- ...did tell me there are 4 muscles of the cervix and that one had shorted quite dramatically But he was quite happy with it and he thought everything would be ok (9.29-31)
- ...asking what sex the baby was (11.29)
- It is an incredibly stressful emotional time and people can't think clearly. Especially a women who has just given birth and has got all her hormones raging and has lost her baby. I mean, how do you MAKE a decision at that point? (11.32-13.2)
- I was phoning the hospital record section to find out if they had taken photo's or had any photo's on record , it really drove me nuts that I didn't know what they child looked like (12.15-16)
- It should be a POLICY in hospitals you know in that scenario to have photo's on record (12.31-32)
- ...couldn't be in that hospital another night. I didn't feel it was of any benefit to me emotionally (14.5-6)
- ...the one incredible strength about the gynecologist I have is that he NEVER downplays the emotional side. He totally ... he analyzed the whole physical thing what had went wrong and you know why it happened and all the questions that we asked he explained everything and he kept saying to me just deal with your emotions. Don't let anyone tell you that this is the right way or this is the wrong way your emotional health is as important as your physical health and you know you and D if you need counseling I can recommend (15.20-25)
- ...he said to me he was going to write a book on me (17.9)
- I'll never forget this (he) left a fertility patient in the middle of a pick-up to do this suture. He said having been through what he had been through with me he just wasn't happy to let anybody else do it (18.26-28)
- ...Dr. E had warned me (27.37)
- The staff by then were like my family, everybody knew exactly who I was (28.25-26)
- ...made the call to Dr. E from next to my bed and he was busy getting into the car with his family on his way to Plett they had loaded the car and everything and he said I'm coming now ?. He put his whole family and his trip on hold and shot into the hospital (29.2-4)
- Dr. E and Dr. R were incredible I mean they each stood on one side holding my hands telling me what's happening and that they can't do anything until the blood arrives (29.21-23)
- I FORCED them to let me go to the funeral you know they didn't want me to go and on the Friday, but I said there is no way you are keeping me in this hospital while you bury my baby (34.4-6)

(16) Religious Context

- I don't believe in God I mean it's not that I don't believe in God. I'm not religious and I don't I never ever turned to God for support or anything I never prayed I never did. HE (meaning D) did. He hasn't set foot in a church since he was 5 years old but when Amanda and Sally were in the intensive care unit he went to the chapel EVERY day. Which blew my mind totally because he's a COMPLETE atheist. He doesn't believe in God at all (36.21-25)

(17) Long term consequences

- NOW LONG TERM there are a lot of issues that remain unresolvedseparationthese things have almost built a wall between us (22.5-12)
- I didn't think that it really hurt our relationship. It's only now with this whole separation that I do realize how much damage it did do (34.28-29)

(18) Regrets

- ...never named them, it wasn't, I regret it now (22.26)
- I wish I had spend more time in the nursery I should have ignored the physical pain and should just have been stronger physically and been there with them (33.26-27)

(19) Financial Context

- Whatever it cost it was just going to be done. Money was NEVER an issue. It didn't matter where it came from, I didn't care whose pocket it came out of... but whatever needed to be done was going to be done as far as I was concerned... I didn't care how or where or who, whether it was my father or (husband) or we had to see our house... whatever it cost, it was just going to be done..... As far as I was concerned, I was having the best possible care (27.16-17)

(20) How subsequent pregnancies were affected

- ...I did have support injections (6.28)
- ...IMMEDIATELY thought it was the pregnancy and went into panic mode (7.8-9)
- ...I had started to bleed and that's when panic set in (9.8)
- I had accepted that I would probably have to spend the rest of the pregnancy in the hospital but that was fine (19.1)
- I've got to go home to bed now. I'm like 5 minutes pregnant but I gotta go home to bed NOW (26.29-30)
- I just wanted to go home and go to bed whatever decisions have to be made they could be made from my bed. I didn't want to WALK, I didn't want to go to the toilet, I didn't want to do ANYTHING. I just wanted to lie in that bed and wait for 9 months. That's what I did (26.33-27.3)

- ...I was spending as much time on my back as I could (27.5)
- ...never got out of bed for anything. I had a bath once every 3 days, hideously disgusting, I washed my hair once a week. I was disgusting. I just REFUSED to take any chances Went to the toilet as little as possible and just got up one a week to go for a scan (27.30-32)
- ...I went into hospital and that became my home. I stayed there on my back, used a bedpan, I was taking absolutely NO CHANCES, NOTHING NOTHING NOTHING at all (27.35-36)

(21) What society demands/expects

- ...actually now when I think about it, its bizarre (10.9)
- I should have been certainly emotionally I think I should have been a wreck by then (10.11)
- I SHOULD have been there for them (31.1)

(22) Remembering days and times

- On the Sunday night and I lay in the hospital until the Monday by the Tuesday evening my contractions had stopped completely and I was still only 4cm dilated (9.21)
- ...by the Wednesday (9.24)
- On the Wednesday morning and on the Thursday afternoon my waters broke (9.33)
- ...took the stitch out on the Thursday afternoon (10.17)
- ...went through the whole of Friday (10.22)
- ...Tuesday night and D left at about 8 to come home (14.4)
- The Saturday night and this was the Sunday evening (19.26)
- ...the Sunday night ... by the Monday (20.17-18)
- On the Friday (34.5)
- Amanda died on the Thursday like Thursday late evening and at 2 o'clock on the Saturday (34.12)

(23) Who they first turned to for help

- My mother moved in with us because D had to go back to work and I didn't want to be alone by myself at home I needed the support emotionally and physically (14.17-18)

(24) Thoughts women have about themselves

- I certainly never considered that I wasn't going to be able to have a child (5.11-12)
- I NEVER in my wildest dreams imagined that I would struggle or that it would be a repeated thing that would happen to me (6.20-22)
- ...you know I had this curiosity and I remembered NOT knowing what answer to give (12.7-8)
- I've always felt that I would be a good mother always known in my heart that I would have been a capable mother that I would it would be the one thing in my life that I would be good at (36.30-32)

- ...it's just the one thing in life that has always felt right for me (36.32-33)
- ...'You've got childbearing hips'. I'll NEVER forget that (37.3)
- ...It's almost like I've always known that I would be a good mother I was MEANT to be her mother (37.8)

Appendix 7

Summary of Womens' Experiences and Needs

